



22 May 2020

## **SURVEY FATIGUE**

Yes, we have a name for it. Many of you will have noticed that there are a lot of online surveys going out to the community in recent months, and it's not just in CF circles.

The COVID-19 crisis has brought many operations to a standstill in universities and research centres across the globe. Certain institutions have responded by going into 'intelligence gathering' mode and using this downtime to prepare for new big projects after Lockdown.

It's the corporate equivalent of my youngest son trying to learn Harmonica during the COVID-19 Quarantine, and just like my youngest son, it makes a lot of noise but has the best intentions.

Cystic Fibrosis (CF) is a rare disease and online surveys tend to reach only a sliver of their demographic targets. This means that the ones who do step up for us and our research partners are doing an extremely valuable service for the cause and they are certainly amplifying their personal say in the future of CF research.

We want everyone to have their say.

Community consultation works for everyone. Every year we have big pharmaceutical asking us to arrange consumer feedback because they genuinely want to know how to improve their products. We all want to reduce the burden of CF and we all want to improve health outcomes.

If you have a spare moment, I would urge you to click through one of the links below because your voice truly matters, you might just hold a piece of the puzzle.

CFA's Research and Advocacy Priority Setting Survey:

<https://bit.ly/3bJTp5u>

ACI Models of Care:

<https://bit.ly/3b4SywZ>

Project Verona (paid):

<https://www.surveymonkey.com/r/VertexCF>

Flinders University's 'Perceptions of Gene Therapy for CF' Survey:

[https://qualtrics.flinders.edu.au/ife/form/SV\\_8DhrwEr6nEInVSI](https://qualtrics.flinders.edu.au/ife/form/SV_8DhrwEr6nEInVSI)

Kind regards

A handwritten signature in black ink that reads "Nettie Burke". The signature is written in a cursive, flowing style.

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